

2025 DEVELOPMENTAL DISABILITIES LEGISLATIVE SYMPOSIUM REPORT

For the Washington State
Developmental Disabilities
Legislative Advocacy Caucus

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ORGANIZED BY THE ARC OF WASHINGTON STATE

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EXECUTIVE SUMMARY

The 2025 Developmental Disabilities Legislative Symposium, held in Seattle from June 11–13, 2025, was the first bipartisan national gathering of state legislators focused on addressing critical issues affecting individuals with intellectual and developmental disabilities (IDD) and their families. Organized by The Arc of Washington State, the symposium aimed to uncover and challenge barriers to belonging, inclusion, and well-being, while addressing policies that hinder full community participation and create challenges within existing care systems.

The symposium's unique design moved from national learning to local action. After two days of policy examination and cross-state dialogue, Washington State legislators posed critical questions to their own constituents during a facilitated community dialogue session. Approximately 100 community members, including self-advocates, family members, direct support professionals, policy experts, and organizational leaders, participated in conversations that directly shaped the policy priorities contained in this report.

From these conversations, six themes emerged that demand both immediate attention and sustained commitment across multiple legislative sessions. **Dismantling Systemic Barriers and Building Equitable Access** centers racial equity and repair as foundational to meaningful reform. **Workforce Investment and Support** addresses the crisis in direct support professional retention and compensation. **Homes for All: Building Integrated and Accessible Communities** tackles housing barriers and opportunities needed for full inclusion. **Empowering Self-Advocates and Families** ensures that people with lived experience drive policy development. **Data-Driven Transformation** creates accountability through transparent information.

Bridging the Digital Divide addresses technology access as essential infrastructure for participation and independence.

The insights and commitments generated through this symposium provide the foundation for comprehensive policy reforms that advance the rights of people with IDD. The Washington State DD Legislative Advocacy Caucus stands positioned to formalize this work through dedicated policy-making structures, multi-biennia strategic planning, and coalition-building that amplifies the voices of leadership within the IDD community.

INTRODUCTION

The first two days of the 2025 Developmental Disabilities Legislative Symposium brought together state legislators from across the nation to learn from experts, engage in critical dialogue, and examine the complex challenges facing people with IDD. These intensive sessions created a foundation of shared understanding about systemic barriers, policy innovations, and collaborative opportunities that transcend state boundaries, while highlighting the need for coordinated action, particularly in the face of federal policy uncertainty.

Building on this national perspective, Washington State legislators identified critical questions where they sought wisdom and input directly from their constituents. Day three transformed the symposium into a community-driven dialogue, with each participating legislator hosting a table focused on a specific policy challenge they face in their work.

Community Voices in Action

The result was a generative dialogue between policymakers and the people most affected by their decisions. Approximately 100 community members, including self-advocates, families, direct support professionals, policy experts, and community advocates, participated in a World Café format, rotating through facilitated conversations to provide insights, share experiences, and identify innovative solutions. This approach ensured that multiple perspectives and lived experiences directly informed the policy priorities and recommendations that emerged.



Legislative Leadership

Representatives Entenman, Gregerson, Farivar, and Macri, along with Senator Wilson and Bea Rector, interim Secretary of Washington State Department of Social and Health Services, each facilitated discussions around critical areas, summarized below. They were also joined by Kris Pederson and Dr. Tonik Joseph from leadership in the newly formed Home and Community Living Administration, and Upkar Mangat from leadership in the newly formed Behavioral Health and Habilitation Administration.

PRIORITIES AND STRATEGIC OPPORTUNITIES

The day's conversations explored six critical areas through facilitated small group discussions:

- **Representative Entenman – Racial Equity and Repair:** How are people of color part of this story? What is our responsibility for repair and meaningful inclusion?
- **Representative Gregerson – Digital Equity and Inclusion:** How do we close the gap for the IDD community in our increasingly digital world?
- **Senator Wilson – System Flexibility and Person-Centered Services:** How do we meet the needs of people with more flexibility? What would a tiered support system look like instead of siloed waivers?
- **Bea Rector, Interim Secretary of DSHS – Priority Gap Analysis:** If we could do three things to address the biggest gaps based on needs, what would they be?
- **Representative Farivar – Strategic Storytelling and Coalition Building:** What have we learned about how to tell our story that will help us be more effective on issues of deep controversy within our community?

- **Representative Macri – Housing Diversity and Community Integration:** How do we ensure the right diversity of housing options to meet people's needs?

From these conversations, six predominant themes emerged for the Washington State DD Legislative Advocacy Caucus, described below. Detailed summary notes from each table conversation are available in the Appendix, providing additional context and specific insights that informed these overarching themes.

Dismantling Systemic Barriers and Building Equitable Access

The Imperative: Washington's IDD system perpetuates racial disparities and historical exclusion that demand urgent, systematic action. Black, indigenous, and other communities of color have been systematically excluded from services, decision-making, and leadership roles while experiencing disproportionate harm from punitive and inadequate systems. Creating meaningful equity requires accountability, repair, and the redistribution of power and resources to center those most affected by systemic failures.

Current Challenges:

- BIPOC-led organizations systematically underfunded compared to white-led institutions.
- Families who speak languages other than English excluded from critical conversations due to inadequate interpretation and cultural navigation support.



- Historical harm from forced institutionalization and discriminatory practices remains unacknowledged and unrepaired.
- Complex eligibility systems and bureaucratic barriers disproportionately impact families of color and immigrant communities.

“Historically, people of color were excluded from the decision-making table. To learn from them, we need to support BIPOC-led orgs. Once these organizations are at the table, we can learn from them and support their direction and vision.”

– Community Participant

Call to Action:

- **Establish a Formal Policy Space:** Champion policy that directly confronts current and historical anti-blackness and racial inequities within the IDD system, creating a foundation for long-term justice.
- **Prioritize Equity-Driven Funding:** Implement funding models that directly support BIPOC-led organizations and community-based initiatives, ensuring resources flow to organizations led by and serving communities of color rather than trickling down through white-led institutions.

- **Establish Comprehensive Language and Cultural Access:** Mandate linguistically and culturally appropriate, community-based services across all IDD programs, including trained cultural navigators, community-based interpretation, and materials developed in partnership with diverse communities.
- **Transform Data Collection and Accountability:** Require disaggregated data collection by race, ethnicity, language, and other key demographics to identify disparities, track progress, and ensure transparent accountability for equitable outcomes.

Workforce Investment and Support

The Imperative: A stable, skilled workforce is essential to meeting the needs of people with IDD and their families. Direct support professionals (DSPs) provide critical community-based services yet face systemic undervaluation through inadequate compensation, limited career pathways, and challenging working conditions.

Current Challenges:

- Limited professional development opportunities and career advancement pathways.
- High turnover rates creating instability and inconsistent care quality.
- Aging family caregivers providing the majority of support without adequate transition planning.
- Insufficient training and support for complex behavioral and medical needs.

- Rural areas experiencing acute shortages and service gaps.

“Most relief comes from family members – who are aging out.”

– Community Participant



Call to Action:

- **Raise the Bar for Compensation:** Advocate for competitive wages, comprehensive benefits, and ongoing professional development opportunities for DSPs, attracting and retaining a skilled workforce.
- **Create Career Pathways:** Develop structured career advancement opportunities, specialized training programs, and educational partnerships that enable DSPs to build expertise in supporting individuals with complex needs while advancing professionally.
- **Address Intersectional Workforce Challenges:** Recognize the interconnectedness of IDD, aging, and childcare workforce challenges, developing coordinated strategies that address affordable, local housing for care workers, transportation access, and sustainable career development across care sectors.

Homes for All: Building Integrated and Accessible Communities

The Imperative: Housing is a fundamental human right that enables community participation, personal autonomy, and quality of life. Community members highlighted the critical shortage of truly accessible and dignified housing options. Creating diverse, affordable, accessible, and integrated housing requires systematic reform of zoning laws, flexible funding mechanisms, and service delivery models to ensure genuine choice and community integration.

Current Challenges:

- Severe accessibility gaps across housing markets, with private Type 1 apartments unavailable to those who need them most.
- Zoning restrictions that prevent innovative housing models like ADUs, cooperatives, and shared living arrangements.
- Siloed funding streams that disconnect housing access from necessary community-based services or ability to pool money for cooperative models.
- Lack of community-based alternatives that force people into inappropriate placements.
- Income restrictions and bureaucratic barriers limit housing choice and stability.



“I was looking for an apartment in Seattle. In the whole city, there were no apartments available that were accessible for me and my needs.”

– Community Participant

Call to Action:

- **Transform Zoning and Housing Policy:** Reform zoning regulations to promote diverse housing models, including ADU adaptations, cooperative housing, shared living arrangements, and accessible duplex/triplex developments that provide space while maintaining community connection.
- **Invest in Community Infrastructure:** Develop funding mechanisms that link housing access with wraparound community-based services, ensuring that people can access both appropriate housing and the support they need to thrive in community settings.
- **Champion Person-Centered Housing:** Ensure that individuals have genuine choice over their living arrangements, reflecting their unique preferences and needs.
- **Center Disability Voices in Housing Design:** Embed the “Nothing for us without us” principle into housing by ensuring that people with IDD lead housing design, policy development, and community planning processes.

Empowering Self-Advocates and Families

The Imperative: The foundational principle of “Nothing About Us Without Us” must evolve from consultation to genuine partnership in policy development and implementation. Community members emphasized the challenge of repeatedly advocating for basic recognition while highlighting the need for sustainable systems that center self-advocate voices and leadership.

Current Challenges:

- Complex, multi-step eligibility processes that create barriers to accessing community-based services, with unclear pathways that may discourage participation.
- Absence of systematic navigation support, particularly cultural navigators and interpreters who understand both community needs and system requirements.
- Language and cultural barriers that systematically exclude multilingual families from critical conversations and decision-making processes.
- Tokenistic inclusion practices where communities of color report feeling reduced to diversity checkboxes rather than valued as essential partners.

“Self-advocates—those with lived experience—need to tell their story, but it can be exhausting to tell and tell again.”

– Community Participant

- Internal community divisions between different advocacy perspectives that can weaken collective advocacy efforts

Call to Action:

- **Create Accessible Resources:** Require plain language, user-friendly resources and information that empowers individuals with DD and their families to navigate the system and advocate for their rights.

- **Establish Comprehensive Navigation**

Infrastructure: Create a network of well-trained navigators with deep IDD-specific knowledge, including cultural navigators and interpreters who provide support for multicultural and multilingual families to understand their rights and access community-based services effectively.

- **Invest in Self-Advocacy Leadership Development:** Fund peer-led programs that position people with IDD as trainers and co-designers of community-based services, supporting leadership development that builds collective advocacy capacity while reducing the burden on individual advocates to repeatedly educate systems about basic needs and rights.
- **Ensure Authentic Participation and Co-Design:** Move beyond tokenistic inclusion by ensuring that people with lived experience hold genuine decision-making power rather than advisory roles, aligning with national best practices that recognize self-advocates as policy experts whose expertise is essential to effective system reform.



Data-Driven Transformation: Ensuring Accountability and Impact

The Imperative: Effective policy requires robust data collection, analysis, and transparency to identify disparities, track progress, and ensure accountability. Community members emphasized that data disaggregation matters, particularly for demonstrating how community-based services are working for communities of color.

Current Challenges:

- Significant gaps in data disaggregation obscure racial, ethnic, and geographic disparities in service access and outcomes.
- Absence of systematic feedback mechanisms from people with IDD about the actual usefulness of community-based services and supports.
- Unclear distinction between what is federally mandated versus state policy versus outdated procedures that could be reformed.
- Insufficient community involvement in determining evaluation priorities and interpreting data for system improvement.



“Data disaggregation by disability and race is essential to track equity gaps in access.”

– Community Participant

Call to Action:

- **Mandate Comprehensive Data Disaggregation:** Require collection and analysis of data by race, ethnicity, disability type, geographic location, and other key demographics across all IDD programs.
- **Promote Transparency in Funding and Outcomes:** Ensure that data about funding flows, service outcomes, and system performance is readily available to the public in accessible formats.
- **Develop Person-Centered Outcome Metrics:** Move beyond service utilization statistics toward measuring outcomes like community integration, self-determination, housing stability, and quality of life, while distinguishing between federal requirements and state policies that could be reformed to better serve community needs.

Bridging the Digital Divide: Accessibility and Technology for All

The Imperative: Symposium participants emphasized the strategic and essential role of technology in community participation, employment, healthcare, and social connection. Community members noted that the COVID-19 pandemic demonstrated both the critical importance of technology and the severe inequities in access that exclude many people with IDD from digital opportunities. Bridging the digital divide requires

addressing the “three-legged stool” of affordable internet, accessible devices, and ongoing training and support.

“Tech is only empowering if you’re taught how to use it.”

– Community Participant



Current Challenges:

- Barriers to accessing affordable, reliable internet, particularly in rural areas and group homes.
- Lack of accessible devices and assistive technology that meet diverse needs.
- Insufficient digital literacy training for people with IDD, families, and support professionals.

Call to Action:

- **Ensure Affordable Internet Access:** Advocate for policies that make high-speed internet accessible and affordable for all Washingtonians.
- **Invest in Accessible Technology Development:** Support the development of assistive technologies, accessible devices, and user-friendly platforms that empower people with IDD to participate fully in digital life.
- **Provide Ongoing Training and Support:** Fund ongoing training and support programs that build digital skills for people with IDD, their families, and support professionals, with emphasis on peer-led and culturally responsive approaches.
- **Mandate Accessible Digital Design:** Require that all state-funded websites, applications, and digital services meet accessibility standards.

RECOMMENDATIONS FOR THE CAUCUS:

Based on the community input and legislative discussions from the Symposium, the following recommendations outline specific actions for the Washington State DD Legislative Advocacy Caucus to implement over the coming biennia. These recommendations surfaced directly from stakeholder conversations and represent priority, catalytic focus areas for sustained legislative actions. The Caucus is encouraged to adopt these structural and procedural recommendations to ensure effective, community-centered policy development that advances the six themes identified in this report.

Formalize a Policy-Making Space: Establish the Caucus as a formal entity with dedicated staffing, defined meeting schedules, and clear protocols for policy development. This may include creating standing committees aligned with strategic priorities and developing coordinated processes for tracking bill progress and measuring policy impact across sessions.

Develop a Strategic Plan: Create a multi-biennial plan that spans multiple legislative sessions, establishing clear priorities, timelines, and measurable outcomes for each of the six strategic themes and other priorities for IDD legislation. This plan should identify which reforms can be achieved through administrative action versus legislative change, establish realistic timelines for major system reforms, and include contingency strategies for responding to federal policy changes that affect state IDD community-based services.

Build Coalitions: Partner strategically with organizations across sectors to build the political power necessary for advancing complex policy reforms. Effective coalitions amplify legislative influence by combining diverse constituencies, expanding voter bases, and creating broad-based pressure for change that individual organizations or legislators cannot achieve alone. Coalition leadership should reflect the

diversity of the IDD community, with particular attention to ensuring that people with lived experience hold leadership roles.

Prioritize Intersectional and Systemic Solutions: Focus legislative efforts on addressing root causes rather than symptoms by targeting policies that affect multiple systems simultaneously. This includes pursuing reforms that address the intersection of housing, healthcare, education, and employment policies, recognizing that siloed approaches often perpetuate the fragmentation that community members identified as a core barrier to accessing appropriate support.

Champion Equity: Integrate equity analysis into all policy developmental processes, including requiring equity impact assessments for proposed legislation, mandating disaggregated data collection in new programs, and ensuring that budget allocations prioritize closing documented disparities in service access and outcomes for communities of color and multilingual communities.

Strengthen Accountability Mechanisms: Create systematic processes for measuring policy effectiveness and maintaining community engagement beyond the legislative session. This may include conducting annual community forums to assess progress on strategic themes, commissioning evaluations of major policy changes, and establishing clear metrics for determining when course corrections are needed in policy implementation.

CONCLUSION

The conversations from the 2025 Developmental Disabilities Legislative Symposium reveal the sophisticated understanding that communities have about systemic failures, policy gaps, and practical innovations

needed for meaningful reform. Participants demonstrated that when policy solutions center the experiences of people with IDD, they create benefits that extend far beyond disability services. Their insights into housing, workforce, technology, and equity challenges show how designing systems with those most systemically excluded at the center generates better outcomes for entire communities. The expertise of the IDD community, combined with legislative commitment to sustained collaborative action, creates the conditions for addressing interconnected barriers while strengthening the social and economic infrastructure that determines whether cities and communities can truly thrive.

This approach translates into concrete policy wins across multiple sectors. Universal broadband investments strengthen economic opportunity for all residents while ensuring people with disabilities can access remote support and employment. Diverse housing models and zoning reforms address affordability crises for working families and seniors while creating the integrated living options that people with IDD need to thrive. Direct support professional wage increases and training programs build the care workforce infrastructure that serves aging populations across the economic spectrum while providing quality support for people with complex needs.

The Washington State DD Legislative Advocacy Caucus has the opportunity to amplify the powerful advocacy and innovation within the IDD community to transform Washington State's approach to disability policy. The 2025 Symposium created unprecedented conditions for bipartisan legislative commitment and sustained action. The Caucus can build on this foundation by taking tangible steps to formalize its policy-making infrastructure and build the political power necessary for complex systems reforms. The momentum exists, the time is now, and the community is ready for the sustained leadership that the Caucus can provide.



APPENDIX

Group 1: Rep. Entenman

Guiding Questions:

- *How are people of color part of this story?*
- *How have people of color been excluded?*
- *What is our responsibility for repair and apology?*
- *What is our responsibility for inviting people into the room?*

Key themes and illustrative quotes:

1. Acknowledging Harm and Seeking Repair

Participants called for formal recognition of harm by state-funded agencies and systems, and the development of models of repair rooted in accountability and community leadership.

- “An apology will acknowledge the harm and also call to repair with actions → Bring representation of different communities to learn what’s needed.”
- “Apology must include action to right the wrong.”

- “Is an apology from the same people who caused the harm worth anything? What is really needed = ACTION.”

2. Anti-Blackness and Systemic Racism in the IDD System

Participants highlighted persistent racism in white-led organizations, schooling, and systems that continue to exclude and harm Black and Brown communities.

- “Anti-Blackness showing up in system → Old assumptions + racialized views about IDD + who is deserving.”
- “Normalization of funding white-led IDD orgs → No acknowledgment that BIPOC orgs are not getting same funds.”
- “No apology to forced institutions → No apology to Black, Indigenous, POC communities harmed by systems.”
- “Black students expelled 3x more often than white peers.”
- “Belief rooms” in schools labeled “calm rooms” → *More violence, not help.*

3. Representation, Leadership, and Inclusion

Discussions emphasized the importance of BIPOC-led organizations, disaggregated data, and supporting leaders of color through systemic investment.

- “Organization serving BIPOC communities should be supported to develop and have accessible funding.”
- “We need to support BIPOC-led orgs. Once these organizations are at the table, we can learn from them & support their direction/vision.”

- “Accountability is why services have to be provided only to BIPOC orgs? Yes and...”
- “Why don’t we train Black leaders?”
- “The closing of Black medical schools = lost leaders that more Black leaders could have been.”
- “Participation = people get the justice they need.”
- “It takes care + space.”
- “Open Doors – see repair go to orgs led by people of color now instead of giving money to larger orgs where money trickles down.”

4. Historical Context and Disability Rights Movement

Participants pointed out how the disability rights movement has benefited from earlier civil rights movements without fully acknowledging those roots.

- “Tell the whole history of how civil rights movement opened doors + provided ethical support for disability rights movement.”
- “Thanks to unpaid labor and persistent advocacy, I and my family enjoy freedom and opportunity.”
- “When the disability slogan ‘nothing about me without me’ was taken from another oppressed group, we need to acknowledge that.”

5. Access, Navigation, and Structural Barriers

Barriers persist in the form of poor language access, lack of trust, and systems designed without BIPOC families in mind.

- “The DD system does not come w/ a cultural navigator or interpreter for how to meet these needs.”
- “Families who speak languages other than English are often left out of critical conversations.”

- “No system to support parents to understand their rights → Need systematic support for multi-cultural families & multilingual.”
- “Development spaces were not inclusive → Found community in churches.”
- “Loop spaces want to serve IDD BIPOC communities.”
- “Community inclusion is beyond our identities. Systems are built in ideas that leave BIPOC out.”

7. Legislative Possibilities & Next Steps

- **Potential next action:** Introduce a bill requesting a formal *governor-issued apology* and a *budget proviso* for reparations.
- **Suggested process:** Hold a larger stakeholder meeting to begin shaping this effort and discuss what meaningful repair could look like, including investments in BIPOC-led organizations.
- **Key framework referenced:** *Acknowledgement* → *Redress* → *Repair*

Group 2: Rep. Gregerson

Guiding Question:

How to close the gap on digital equity and inclusion for the IDD community?

Key themes and illustrative quotes:

1. The Three-Legged Stool of Digital Equity

Participants emphasized that digital equity for the IDD community requires a “three-legged stool” approach:

affordable broadband, accessible devices, and ongoing support for access and training. Each leg is essential for meaningful participation in digital life.

- “We need tools, not just tablets.”
- “Tech is only empowering if you’re taught to use it.”
- “Just because something is available online doesn’t mean it’s accessible.”

2. Structural Barriers and Systemic Inequities

Racism, ableism, and underfunding were named as root causes of ongoing digital inequity. Participants described how families must navigate outdated websites, complex login systems, and red tape just to access Wi-Fi programs or online services.

- “Digital equity means nothing if folks don’t know what services are available.”
- “There are so many steps to even figure out what you’re eligible for.”
- “Current broadband maps underreport challenges in group homes or multi-family IDD households.”

5. Technology is a Lifeline but Access Remains Unequal

The group discussed how critical technology has become for people with disabilities, particularly in rural or under-resourced areas. However, major gaps in access to devices, affordable internet, plain language platforms, and tech training persist. Participants shared creative ideas like smart home grants, peer-led tech plans, and apps that connect people with providers.

- “Tech access has been a lifeline, not optional.”
- “Remote supports mean tech at any time, not time-dependent.”
- “App like Tinder but for finding reliable QMHP/IDD providers.”

3. Community-Based Solutions and Cultural Relevance

Equity efforts must be shaped by communities themselves. Participants emphasized the importance of trusted messengers, culturally responsive digital navigators, and peer-led programs that empower people with IDD as leaders and co-designers of tech solutions.

- “Programs must address multilingual support, especially in rural and immigrant communities.”
- “We should have peer-led tech support programs with IDD folks as trainers.”
- “Community spaces like libraries need to be part of digital access plans.”

4. Inclusion from the Start in Statewide Planning

Participants called for people with IDD to be involved from the beginning of any digital planning efforts. State agencies and inter-agency collaborations should include people with lived experience in design, implementation, and evaluation.

- “Training must go beyond how to use Zoom. It’s about how tech supports independence and connection.”
- “We need a centralized platform for navigating digital supports across DDA, education, and libraries.”
- “Nothing about us without us.”

5. Innovation and Policy Gaps

Participants shared bold ideas to improve digital equity, from funding low-tech solutions like phone trees to simplifying apps for ease of use. They stressed the need for grants that prioritize inclusive design and policies informed by data disaggregated by race and disability.

- “Fund pilots that test both low-tech and high-tech approaches.”
- “We need ongoing feedback loops from IDD individuals on how useful digital tools actually are.”
- “Grants should prioritize orgs with inclusive outreach and co-designed materials.”

Group 3: Senator Wilson

Guiding Questions:

- *How do we meet the needs of people with more flexibility?*
- *What would a tiered support system look like instead of siloed waivers?*

Key themes and illustrative quotes:

1. The Problem with Siloed Waivers

Participants described the waiver system as rigid and fragmented, making it difficult to access needed community-based services across categories. The lack of portability between waivers leaves individuals trapped in “service silos,” where what they are eligible for does not necessarily match what they need. There was strong support for transitioning away from tiered systems toward a more flexible, menu-based approach that allows families to choose community-based services based on evolving needs.

- “If you need something in another waiver, you’re siloed and you can’t access it.”
- “Same service labeled something different depending on waiver.”
- “You have to know what you need to even ask for it—but what if you don’t?”
- “What if you had a direct cash amount to spend as you see fit?”
- “Money should follow the person, not the program, not the house, not the location.”

2. Inconsistent Access and Case Management Inequities

Many participants emphasized the inequities created by current case management structures. Families with multiple children often deal with separate caseworkers and inconsistent care levels. Some case managers act as “gatekeepers” rather than as navigators or advocates.

- “Case management isn’t working.”
- “One family with multiple children will have different caseworkers and different levels of care.”
- “Caseworkers act like gatekeepers—there’s inequity in what people get.”

3. Barriers to Access in Rural and Underserved Areas

Participants flagged geographic disparities in access to community-based services, including employment, transportation, and specialized providers. In rural counties, gaps in service delivery and a lack of flexible funding options contribute to long-term instability and crisis cycles.

- “There are huge gaps in services across counties—especially rural ones.”
- “We need flexibility in funding, not if/then options that don’t reflect local realities.”
- “Community high support needs and pay inequity cause crisis cycling in and out of systems.”

4. Reimagining the System: Structural and Legislative Levers

Attendees urged a thorough reexamination of how the system is built, asking for an “unstacking of the bricks” to rebuild with intention. They emphasized the need to separate what is federally mandated from what is procedurally enforced at the state or agency level, and to explore models like direct cash assistance or self-directed waivers.

- “Unstack the bricks (without harm) to rebuild the system.”
- “Don’t let ‘reimagine’ create new silos.”
- “We need to understand what’s federal, what’s state, and what’s just outdated policy.”

5. Workforce Shortages and Inadequate Support for Caregivers

Participants expressed concern about the shortage of the direct service provider (DSP) workforce noting high turnover, low pay, and a lack of training. Family caregivers are providing the majority of support without adequate systems in place to support transitions or long term sustainability, especially as these caregivers age.

- “50% turnover among careworkers.”
- “Most relief comes from family members—who are aging out.”
- “How do we help caregivers feel invested in their work and their value?”

Group 4: Bea Rector

Guiding Question:

If we could do three things to address the biggest gaps based on needs, what would they be?

Key themes and illustrative quotes:

1. Workforce Investment and Direct Support Professional (DSP) Retention

Participants called for targeted investment in direct support professionals (DSPs) through competitive wages, practical training, and long-term support. They also urged a review of family caregiver training requirements to ensure relevance and accessibility.

- “Invest in DSPs: pay, training, and support.”
- “End the community provider vs. state provider pay gap.”

- “Training family members: is the training that’s currently required even relevant or needed?”

2. Lack of Appropriate Providers, Settings, and Crisis Stabilization Options

Participants called for more flexible, person-centered care settings to reduce reliance on hospitals and other restrictive placements. They emphasized the need for integrated funding, regional provider networks, crisis stabilization infrastructure outside of emergency rooms, and a coordinated statewide plan to expand appropriate options.

- “People are stuck in acute hospitals, which are not appropriate, quality places tailored to their needs.”
- “Siloed funding and geography make it hard to find care that matches people’s preferences.”
- “We need a comprehensive plan like the children’s BH workgroup to create more options.”
- “We need a place for crisis stabilization within 48 hours to a week.”
- “RHCs have medical care on-site—why not use that for short-term crisis placements?”

3. Complex, Opaque Systems That Are Hard to Navigate

The IDD system was described as overly complicated and inaccessible, especially at the entry point. People struggle to find out whether they’re eligible for services, and the burden of navigation falls heavily on families without adequate support.

- “There are multiple steps just to find out if you're eligible.”
- “Is the first step designed to slow people down?”
- “We need a cadre of well-trained navigators with deep DD-specific knowledge.”

4. Flexible, Person-Centered Funding That Follows the Individual

Attendees called for reforming funding models so that resources follow the person rather than being tied to rigid programs, settings, or institutional models. This flexibility would support autonomy, cultural and linguistic responsiveness, and equity in service delivery.

- “Funding should follow the person, not the program.”
- “Practice equity by funding BIPOC/DD by-and-for organizations with sustainable resources.”

5. Building Coalitions and Shifting the Narrative

There was a strong call to move beyond scarcity-driven decision-making by building trust, uniting across disabilities, and involving a wider range of voices. Participants stressed the importance of storytelling, proactive engagement, and values-driven leadership.

- “Create a united front. We need to have the hard conversations.”
- “Use video to show the issue. Don’t just tell people about it.”
- “Bring more youth, diversify and expand, lead with trusted messengers.”

Group 5: Rep. Farivar

Guiding Question:

What have we learned about how to tell our story that will help us be more effective on issues of deep controversy within our community?

Key themes and illustrative quotes:

1. Lead with Shared Humanity and Bridge Internal Divisions

Attendees described persistent tension within the disability community, especially between self-advocates and parent advocates. These divides were seen as harmful and distracting from shared goals. Participants emphasized the importance of starting from shared needs such as housing, safety, connection, and

employment, and building messages that center dignity and lived experience. Advocacy should reflect the full picture of people's lives, grounded in values like respect, autonomy, and community.

- “What we all need: housing, food, consistency, safety, healthcare, employment, connection.”
- “We seem to fight each other more than break down barriers.”
- “Reconcile split between DD community.”
- “Internal split between self-advocates ↔ parent advocates.”
- “Build COALITIONS — across disabilities.”

2. Invest in Infrastructure, Stability, and Caregiver Support

Participants emphasized the need for sustained investment in systems that support people with disabilities across their lifespan. This includes higher wages and recognition for paid caregivers, closing pay gaps between institutional and community settings, and infrastructure that fosters long-term stability.

- “Fix the pay gap between community & institutional care providers.”
- “Need to invest \$\$ into infrastructure in the community.”
- “Paid caregivers — value? longevity?”
- “How do we create stability?”
- “Controversy → \$ → scarcity mindset → instability.”

3. Elevate Effective, Inclusive Storytelling

There was strong recognition that storytelling is powerful and a burden. Participants recommended proactive strategies: tailoring messages to different audiences, using video to show rather than just tell, and sharing the burden of advocacy. Trusted messengers and cross-generational voices were seen as key.

- “Self-advocates need to tell their story—but it can be exhausting to tell & tell again.”
- “Use video to SHOW the issue—don’t just tell people about it.”
- “Take strategic bites—build more trust.”
- “Welcome ALL generations.”
- “We evolve. Trusted messengers.”
- “Provide tangible support... to connect more people with more legislators more often.”

4. Simplify Systems and Empower Navigators

The complexity of the IDD system continues to be a major barrier. Participants called for streamlined processes, early engagement, and navigators who are well-trained in disability-specific resources. Building clear pathways for families and individuals was seen as key to increasing access and trust.

- “Navigators who exist need more expertise on IDD.”
- “We need a picture of what navigator ‘types’ exist.”
- “Simplify—start early.”
- “What is the roadmap? Who determines the timeline?”
- “This builds trust.”

Group 6: Rep. Macri

Guiding Question:

Housing – How do we ensure the right diversity of housing options to meet people’s needs?

Key themes and illustrative quotes:

1. The Need for Diverse, Flexible Housing Options

Participants emphasized the rigid and limited nature of current housing options. Many people with disabilities are either forced into inappropriate placements, like adult family homes, or are unable to modify their own homes to remain in them long-term. There was a call for greater flexibility in housing design, zoning, and funding that supports intergenerational living, ADU conversions, and shared housing models.

- “Allow DD funding to pay for permitting for ADUs.”
- “We need to create opportunities for families to develop cooperatives, pooling resources.”

2. Community-Based Services Must Be Integrated With Housing

Participants emphasized that stable, community-based housing requires coordinated access to community-based services like caregiving, healthcare, and assistive technology. When these supports are siloed or unavailable, people are often pushed into institutional placements that don't reflect their needs or preferences.

- “Housing is inextricably linked to support services.”
- “People are forced to go into supported living.”
- “Connect to affordable housing for all so that workforce can be co-located.”

3. Break Down Structural Barriers and Siloes

Systemic issues such as restrictive zoning, siloed funding, and red tape, undermine access and choice. Participants called for clearer pathways and more integrated systems across agencies and jurisdictions.

- “Zoning restrictions are very challenging for freedom in building for needs.”
- “Bring DD into decisions happening right now in zoning.”

- “Anything that can be done to break down these siloes.”

4. Co-Design With People With Disabilities

Inclusive design must center people with lived experience. Participants urged policymakers to involve disabled voices from the start of the design process, rather than only bringing IDD voices in as consultation at the end of the process.

- “Invite people with DD to design this.”
- “Reaching out and involving so that design is responsive and meets varied needs.”
- “Nothing about us without us”

5. Reform Bureaucratic and Financial Systems

Attendees described barriers like income limits, inaccessible Section 8 programs, and excessive administrative complexity. They proposed clearer funding pathways, community-based oversight, and replicable models for inclusive development.

- “Section 8 certificates are no longer available for DD – can this shift?”
- “What would stop us from creating a nonprofit with micro-boards under it so you don’t have to create so many NGOs?”
 - “Could we provide a playbook to help other communities do this? Shared decision-making.”

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For the Washington State Developmental Disabilities Legislative Advocacy Caucus



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